

VIII. COMMUNITY SERVICES FOR PEOPLE WITH MENTAL ILLNESS, DEVELOPMENTAL DISABILITIES OR ALCOHOL OR DRUG ABUSE PROBLEMS

A. What are Community Services?

Community services are services that help people live, learn and work in their own communities as independently as possible, while at the same time helping the person to develop or retain skills. (See Sections V-C and D) For people with significant mental disabilities, they can often mean the difference between institutionalization and life in a normal home and can provide meaningful, productive activities. For example:

- Augie is an older man who has early stage dementia and a heart condition. He has a visiting nurse who visits three times a week and homemaker services twice weekly. His church provides some meals, transportation assistance, and visitors to provide social contact and stimulation. The county manages his funds as representative payee. His county case manager is working to get his family more involved.
- John is chronically mentally ill and has a history of being in and out of hospitals. He now lives on his own with the help of a community support program, which provides drop-in assistance to help him with daily living, social and work activities, and money management, and monitors whether he is taking his medication. If he does not show up for one of his meetings, the program actively goes out and finds him to make sure his treatment needs are met.
- Paul is labeled severely mentally retarded, is nonverbal and has a history of challenging behaviors. He needs support in meeting his self-care needs and he needs a lot of supervision. He spent many years in a state Center for the Developmentally Disabled. Now, with funds from the Community Integration Program, he lives in a group home with two other former Center residents. In his new environment, his communication skills are improving, he has become independent in toileting, and he is learning to do many more things for himself.
- Frieda is also labeled severely mentally retarded. She lives at home with her mother. After graduating from school, she had been home with nothing to do and was losing skills she learned in school. Her boredom and frustration was resulting in anger, tantrums and lack of cooperation. Now she works at a hospital supply room, with support from a job coach who helped design a job she could do and provides on-site support and supervision to her and two other workers who have disabilities. She is learning to get to and from work on her own, is learning better communication skills and behaviors that are acceptable in community settings, and has new pride as an adult who works with other adults, nondisabled as well as disabled.

B. Learning How Your Local Community Service System is Organized

Wisconsin relies on counties as the primary organizers of local community services. The sections below describe the various responsibilities of county government, but counties have a lot of freedom to decide how to assign these responsibilities. Most counties now have single Human Service Departments that combine all or most human service responsibilities. To find out where a particular responsibility lies in your county, you can often get help from the county clerk or the office of the director of the county Aging Unit, Human Service, Community Programs or Social Services Department. You can also look in the telephone book under county government for some of the terms mentioned below. Some other terms used in some counties include "Adult Services" or "Long Term Support."

The system is made more complicated because some services are not run through the county. For example, Home Health and Personal Care agencies are often independent of the county and bill directly for Medical Assistance and Medicare funding.

C. Community Services for People with Mental Illness, Developmental Disabilities or Alcohol or other

Drug use

Wisconsin's Mental Health Act (Chapter 51) creates a county-based system for planning and delivery of community services for people with mental illness, developmental disabilities or alcohol or other drug abuse problems. The county board of supervisors has the primary responsibility for services to residents of the county, and for emergency services to nonresidents.

The county board is required to establish community services departments to carry out the county's responsibility to plan and deliver services. Most counties have now assigned this responsibility to larger human services departments that provide a wide range of services. Others continue to have separate community program departments, often serving multiple counties. Two counties still have separate boards for developmental disability services. The statutes list a broad range of services the community service boards should provide, including evaluation, treatment, community support, residential and vocational services.

Under the bill of rights that applies to clients of the community service boards (see section VI-K), a person has a right to receive prompt and adequate treatment, rehabilitation and educational services appropriate for his or her condition and a right to the least restrictive conditions necessary to achieve the purposes of the program he or she is placed in. However, the law limits these rights to what counties can do with state and federal funds and legally mandated county matching funds. Unfortunately, state and federal funding is not enough to meet the need for services, and many people are on waiting lists for services or are in institutions because needed community support services are not available, even where community services would be more appropriate and less expensive.

One reason for this is that the state and federal governments provide full funding for institutional care under Medical Assistance, but only provide a set amount for community services. Thus, supportive community services not only require county planning and management, but often require county funds.

Since 1981 the state has vastly expanded funding for the Community Options and Community Integration programs. Through these programs, the state has contained growth of institutions and allowed many people to choose to remain in their own homes and communities with individualized support services. (See Section VIII-E)

It is important that the lack of adequate services for a ward should not simply be accepted by a guardian. The first step should be to discuss the issue informally with agency or county staff. If this does not work, the guardian can make a written grievance under the agency's or board's grievance procedure under § 51.61 of the statutes and HFS 94 of the Wisconsin Administrative Code. (See Section VII-G), noting the rights that the guardian thinks have been violated. State law and rules now provide for an appeal to the county and state levels under the grievance procedure, so that an independent review is available. Unfortunately, the law may allow funding to be used as a defense where the only rights violated are those to least restrictive or appropriate services.

In cases where there is a significant violation of a person's rights and the grievance process does not work, a guardian may consider taking legal action under § 51.61, the statute which authorized lawsuits to enforce rights, including a right to attorney fees if the person is successful.

A final method of advocacy is to try to change the service system itself. One of the rights of people in our society is to petition the government for change. While it is not a legal duty of the guardian, it is certainly appropriate for a guardian to act as a spokesperson for the person on public issues. One approach is to ensure that the county agency does not simply ignore unmet need: while a community services department cannot spend money it does not have, it is responsible for identifying unmet needs and developing plans to meet those needs. A good plan can help to ensure that resources are used fairly, and that unmet needs are not ignored. Ultimate funding responsibility lies with the county board and state legislature, and the guardian may wish to contact the person's county supervisor and state legislators concerning gaps in the service system.

D. Social Service Departments

The county Department of Social Services provides a broad range of services which are not necessarily limited to people with mental disabilities but which may be helpful in arranging a package of support services. Social service agencies often have primary responsibility for services for people who are elderly or physically disabled, including funding for an attendant or home worker to provide personal care, meal preparation, housekeeping and chore services in the person's home. In many counties the social service agency is the lead agency for the protective service system and the Community Options Program. Social service departments also operate benefit programs including Medical Assistance and Food Stamps.

If social services or other benefits are denied or cut back, the person usually has a right to a hearing to challenge the agency's action. Notice of how to request a hearing should be given with the notice of the agency's action.

E. County/Tribal Aging Units

Every county and tribe in Wisconsin has a designated "aging unit" responsible for planning and carrying out certain programs for older people, including nutrition programs, transportation, information and referral, benefit specialist services, etc. These units may also manage other long-term care services and elder abuse services, but in any case they can tell you where to find those services in your county.

F. Lead Elder Abuse Agency

The **elder abuse** law requires the county to designate a lead agency to establish an elder abuse reporting system in the county. That agency then coordinates other agencies that are participating in the elder abuse reporting system, identifies agency responsibility for investigation of reports of abuse, neglect, self-neglect and material abuse and arranges for provision of services.

The **elder abuse reporting system agency** has the following functions, in addition to its planning and coordination functions:

- Receiving and either investigating or referring reports of abuse, neglect, self-neglect or material abuse.
- Publicizing the existence of the reporting system.
- Notifying law enforcement officials in appropriate cases.
- Offering and providing needed services, within available funding.

G. Protective Services Agency

Ch. 55 requires each county board of supervisors to designate one or more county departments to act as the *protective services agency*, with responsibility for local planning to implement the protective service system. The county may designate one or more of the following departments: Human Services, Social Services, Community Programs (51.42) and Developmental Disabilities Services (51.437).

Some counties have created agencies with "protective service" in the title. However, the statute is not about creating an agency or unit. It is about distributing protective service responsibilities at the county level so that people in the system know who is supposed to do what before the inevitable report of abuse, neglect and exploitation comes in, and so there is some plan in place to identify and prevent abuse, neglect and exploitation. A county may decide, for example, that abuse and neglect complaints for elders will be handled by the aging unit while those for people with developmental

disabilities will be handled by the community programs unit.

The PSA has responsibility for local planning for the protective service system. In addition, it has been given many specific powers and responsibilities, including:

- Receiving and investigating reports that individuals placed by their guardians in certain settings object to those placements, and ensuring that such placements meet legal requirements. (See Sections V-F and V-H-2)
- Provision of protective services. (See Section V-H-1)
- Petitioning the courts for guardianship, protective placement and protective services.
- Cooperating with the court in securing resources for comprehensive evaluations in protective placement cases.
- Acting as the agency through which protective placements are made, with primary responsibility for implementing and funding appropriate placements.
- Completion of annual reviews of protective placements.
- Development of requirements for annual reports of guardians of the person.
- Making of emergency protective placements.

H. Community Options Program and Community Integration Program

The original Community Options Program (COP) is an effort to provide funding for community services to people who would otherwise qualify for care in a nursing home or facility for people with developmental disabilities. COP provides funds to individually assess people to determine if services can be provided in the community and develop an individual plan for services. If services can be delivered that will meet the person's needs with funds available, COP uses highly flexible state funds to fund those services. Unfortunately, COP funds are limited and not all eligible people can be served.

After the original COP program began, the federal government changed its rules to allow states to get waivers to spend federal Medical Assistance funds to provide community services for people who otherwise would be eligible for certain types of institutional care. Available services include case management, residential support services, day services, work-related services, counseling, daily living skills training, home modification, adaptive equipment, home health, personal care, habilitation, respite, day treatment, and psychosocial services.

The state sets average daily rates for the MA waiver programs. Because these are averages, particular individual plans may provide for funding above or below the average. The state averages are below what the federal government would allow, so if a county does exceed the overall average it can generally use the money it spends to obtain federal reimbursement for 60% of its excess costs. MA waiver services can be combined with COP funding, SSI and MA card services. For a person to participate, the program requires agreement from the county responsible for providing the services and consent from the person or the person's guardian, if any, unless a court orders community placement. Wis. Stat. §§ 46.275(4)(b)1., 2.; 46.277(4)(a); 46.278(5).

Wisconsin is currently operating several waiver programs:

- *Community Integration Program for Residents of State Centers (CIP-1a)*

CIP-1a, § 46.275, provides funding for home and community-based services to people placed out of one of the

three state centers for the developmentally disabled. The state has increased the CIP-1a rate in recent years in an effort to encourage community placements of residents of the state centers. The average daily rates as of July, 1997, were \$153 for new placements and \$125 for continuing placements made before July, 1995. These amounts are designed to cover actual county placement costs, but counties that spend more can be reimbursed for 60% of their excess costs.

- *Community Integration Program for Person with Mental Retardation (CIP-1b)*

CIP-1b, § 46.278, provides funds (an average of \$48.33 per day in 1997) for community placement and services to people with developmental disabilities who are living in nursing homes or intermediate care facilities for the mentally retarded (ICF-MRs) other than the state centers, or who are in the community but would qualify for a level of care provided in an ICF-MR. Funding from the state to provide the state match for CIP-1b is limited, and is most likely to be available for individuals relocated from institutional setting. Counties can almost always obtain the federal matching portion (60%) of CIP-1a if they are willing and able to come up with the 40% state match, from COP Community Aids, or county tax levy funding. State funding and a higher daily rate are available individuals are relocated from a facility that is closing. Section 46.278(6)(e).

- *Community Supported Living Arrangements Waiver*

This waiver is very similar to CIP-1b, but is intended to provide more flexibility and consumer control in the methods of support. The county must provide the state match from COP, Community Aids, or local funds.

- *Brain Injury Waiver*

Services under the Brain Injury Waiver are available to persons with brain injury, as defined in § 51.01(2g), who need service similar to those provided in institutional rehabilitation programs for people with brain injury. The average daily rate is \$170 per day.

- *Community Integration Program for Persons Relocated From or Eligible for Nursing Home Care (CIP-II)*

CIP-II, section 46.277, provides funding to counties for community services for people who are relocated from nursing homes or who need a level of care that MA would pay for in a nursing home. It is available only in counties in which a nursing home has closed or been reduced in size. For example, a county with a 200-bed nursing home might choose to rebuild a 100-bed home and receive CIP-II funding for 100 service “slots” to serve people in community settings. CIP-II is generally not available to serve people who are not elderly and who need services primarily because of chronic mental illness or mental retardation. The average daily rate is \$40.78, and state matching funds are provided up to that rate.

- *Community Options Program-Medical Assistance Waiver (COP-W)*

The COP-W waiver, section 46.27(11), is intended to provide federal funds to supplement the reimbursement usually available under COP for elderly or physically disabled people who need a level of care that MA would pay for in a nursing home. The average daily rate is \$40.78, but local county match may be required.

I. Community Support Services for People with Mental Illness

Community support is a key service for preventing institutionalization of people with persistent mental illness. Section 51.421 requires that each DCP establish a community support program for people with chronic mental illness. Standards for these programs are contained in HFS 63, Wis. Admin. Code. Community support services can now be funded as a Medical Assistance service, making it more affordable for counties. However, unlike most other MA card services, counties must provide the state portion of funding. As a result, local service availability is dependent on county

funding commitments.

J. Home Health and Personal Care Services

Home health (including nursing, home health aide, therapy and medical equipment), private duty nursing and personal care together have recently been the fastest-growing service under the Medical Assistance program. MA does not require that the person be "home-bound" to receive most these services, except for in-home therapy services. These services are now an important part of the long-term support service package for many people, particularly those on waiting lists for other long-term support programs.

Home health and personal care services are arranged through certified providers. For many services, the provider must get prior authorization from the state Bureau of Health Care Financing. Denials of eligibility and denials or reductions of service coverage can be appealed through an administrative fair hearing process.

Medicare also covers nursing and home health aide services, but does not cover personal care. Medicare requires that the person need a skilled nursing or therapy service to be eligible for coverage.

K. Supplemental Security Income Exceptional Expense Supplement

Supplemental Security Income (SSI) provides income maintenance payments to people who are over age 65, blind, or disabled, and who meet income and resource standards. It is an important source of funds for basic living expenses in community settings, particularly because MA waiver rules limit use of MA funds for room and board expenses. People on SSI generally receive both a federal SSI payment and a state "supplement." The federal payment is administered by the Social Security Administration, while the state supplement is now administered separately by the state Department of Health and Family Services. A special increased state supplement level called SSI-E is available for people who need 40 or more hours per month of supportive home care, daily living skills training or community support services. The person must be certified by the county to get this increased payment level.

IX. LEGAL ASSISTANCE

One of the guardian's roles is to advocate for the person in legal proceedings. If the guardian feels strongly that the person's rights or interests have been damaged and that less formal advocacy is not effective, he or she may want to begin a lawsuit to assert those rights or interests.

In choosing an attorney, the guardian or person should not be afraid to call several attorneys to ask about fees and experience in working on issues involving people with disabilities. If you do not know of any lawyers, it may be useful to ask people in similar situations if they can recommend someone. The state bar also runs a referral and information service that can give you the names of lawyers who work on cases like yours. Their number is toll-free: 1-800-363-9082.

When a guardian of a person is appearing on behalf of the ward, the costs of litigation should be expected to be paid out of the ward's estate. Therefore, it is important for the guardian of the person to discuss this with the guardian of the estate and to get the financial support of the estate guardian. If the ward has low income he/she may be eligible for free legal services. If no government legal services program is available, a guardian might be able to locate an attorney who is willing to donate his/her services or, if there is a possibility of recovering damages (money from the people being sued), would be willing to take the case on a contingent fee basis.

Sometimes disputes might arise between the guardian and the ward. In most instances, they will be able to work out an agreement, but it is possible that the dispute will finally have to be resolved by the court. For example, the ward may

wish to get married but the guardian strongly opposes such a marriage. The ward could try to go back to court to get a modification of the findings of incompetency which would return the right to get married. Depending upon the strength of the guardian's opposition and/or degree of incompetency, the guardian could choose to simply appear at the court hearing and ask to testify to the judge as to the reasons why marriage would not be in the ward's best interest. But if the guardian's feelings were extremely strong or the facts of the case were very marginal, the guardian might want to hire an attorney to represent the guardian's position. If the guardian's position prevails, the court may determine that the guardian's court expense shall be paid by the ward's estate if the court first determines that the guardian was fulfilling her/his statutory responsibilities in taking the position. However, since neither victory nor an awarding of attorney fees can generally be assumed, guardians should not count on the ward's estate to pay the guardian costs.

Possible sources of legal advice and assistance are listed in the Appendix.

X. LEARNING MORE

The Appendix contains a resource list of agency names and addresses which can be sources of more information on legal issues, specific disabilities, evaluation resources, long-term support services, and government programs.

The following two books provide greater detail and legal citations on many of the issues discussed in this handbook:

Chapter 51: The Wisconsin Mental Health Law (1993; publication ID # PCS 461).

Chapter 55: The Wisconsin Protective Services Law and Its Application (1994, publication order ID # PCS-460a).

For copies of these publications, contact:

Department of Health and Family Services
Division of Supportive Living
ATTN: Publications Order
One West Wilson St.
P.O. Box 7851
Madison, WI 53707-7851

Requests should be made by either completing a DMS-25 FORMS/PUBLICATIONS ORDER or by sending a written request which includes the publication identification number, the number of copies, your name, a complete return address (including street address) and a phone number where you can be reached in case questions arise.

Other useful reading material includes:

Doubly Silenced: Sexuality, Sexual Abuse and People with Developmental Disabilities. Madison, WI: Wisconsin Council on Developmental Disabilities (1991).

Durable Powers of Attorney for Finances and Other Property. Madison, WI: Elder Law Center.

Elder Abuse: Potential Legal Remedies. Madison, WI: Wisconsin Coalition Against Domestic Violence.

Finding a Way Toward Everyday Lives: The Contribution of Person Centered Planning. Harrisburg, PA: Pennsylvania Office of Mental Retardation (1992). (Copies available from the state Bureau of Developmental Disabilities Services.)

One Step Ahead: Resource Planning for People with Disabilities Who Rely on Supplemental Security Income and Medical Assistance. Madison, WI: Wisconsin Council on Developmental Disabilities (1997).

No Easy Answers: Seeking consensus when considering psychotropic medication for individuals with developmental disabilities. Madison WI: Wisconsin Council on Developmental Disabilities (1996).

Overview of Medical Assistance Lien Law and Estate Recovery Program. Madison, WI: Elder Law Center (1996).

Planning for Future Health Care Decision-Making: DO-IT-YOURSELF PACKET. Madison, WI: Elder Law Center

A guardian may also want to have direct access to relevant laws and rules. These are often available in the reference section of public libraries. Laws and rules that are often important for guardians to be aware of include:

Wisconsin Statutes

- Ch. 46 Social Services (including programs on aging)
- Ch. 49 Public Assistance (including Medical Assistance)
- Ch. 50 Uniform Licensure (including nursing homes, community-based residential facilities, and adult family homes)
- Ch. 51 Alcohol, Drug Abuse, Developmental Disabilities and Mental Health
- Ch. 55 Protective Services
- Ch. 880 Guardianship

Wisconsin Administrative Code

- Ch. HFS 1 Uniform Fee Schedule
- Ch. HFS 61 Community Mental Health Services
- Ch. HFS 63 Community Support Programs for Chronically Mentally Ill Persons
- Ch. HFS 83 Community-Based Residential Facilities
- Ch. HFS 85 Non-Profit Corporation as Guardian
- Ch. HFS 88 Licensed Adult Family Homes
- Ch. HFS 89 Assisted Living Facilities
- Ch. HFS 92 Confidentiality of Treatment Records
- Ch. HFS 94 Patient Rights and Resolution of Patient Grievances
- Ch. HFS 100 Medical Assistance
- Ch. HFS 118 Confidential Information
- Ch. HFS 125 Do-Not-Resuscitate Orders Directed at Emergency Health Care Personnel
- Ch. HFS 131 Hospices
- Ch. HFS 132 Nursing Homes
- Ch. HFS 133 Home Health Agencies
- Ch. HFS 134 Facilities for the Developmentally Disabled